The politics of disability: some implications for geriatricians

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INTRODUCTION

Traditionally marginalized as a social group, disabled people have now become a political force in their own right. The meaning attached to disability has substantially changed over the years and is now a politically valuable 'generic' term. Disability-related benefits are still allocated according to medically-based definitions. Until very recently, all disability-related charitable work and State welfare has been planned for, not by, disabled people. And it is still not sufficiently recognized that at least two-thirds of them are of pensionable age.

THE DISABILITY MOVEMENT

It is now correct to speak of a disability 'movement', significantly influenced by opinion in the USA. The 1990 *Americans with Disabilities Act* was echoed by the *British Disability Discrimination Act* in 1995. Disabled people who are active in the movement have chosen either to work in partnership with established interests or in open challenge: both approaches have produced results.

The movement has generated its own philosophy, a 'social model' of disability which includes a re-examination of commonly used concepts including disability itself. The full implications have yet to be worked out, but many disabled people regard the social model as liberating. Another feature of disability politics is an appeal to rights, which has led to controversy over the *Disability Discrimination Act*.

In 1992 the Royal College of Physicians published *A Charter for Disabled People Using Hospitals* as a joint venture with disabled people's organizations. The College is now supporting a multi-centre audit, again involving disabled people, to explore issues raised by the Charter which include some of the conflicts underlying the Act.

The clinical practice and management responsibilities of geriatricians can and should incorporate working with disabled people as colleagues, assimilating the implications of the social model of disability and recognizing the relevant issues of equality and rights. The disability movement has

produced a valid articulation of a collective view which, despite some shortcomings, should influence the way all clinicians think and behave.

SOCIAL ATTITUDES TO DISABILITY

> Cheated of feature by dissembling nature,
> Deformed, unfinished, sent before my time
> Into this breathing world, scarce half made up,
> And that so lamely and unfashionable
> The dogs bark at me as I halt by them.

At least two disabled writers have quoted these lines from *Richard III*, among many examples of the aversion to disability which pervades history and literature[1,2]. Shakespeare directly links Richard's physical deformity with his criminal behaviour. Simone de Beauvoir has extensively reviewed a similar set of attitudes to old age[3]. The traditional counterweight in Europe and America has been based on Christian charity and the welfare systems of the last century: but condescending kindness can itself be repressive. We still remain less tolerant of people with mental impairments.

Some of the most recent newspaper and television images of disability have included people in wheelchairs demonstrating noisily, for example outside Parliament or against nationwide charity fund-raising by the BBC. In October 1995 the *Disability Discrimination Act* became law, but only after 17 attempts at legislation[4] (p. 2) and parliamentary uproar which had forced the Minister for the Disabled to resign in 1994. For people with traditional views of charity and public service these things were just politics—distasteful, diverting attention from real needs. Foley and Pratt quote a gem from *The Daily Telegraph*.

> The truth is that the disabled cannot manage without the sympathy, and indeed the protection, of the rest of society, and they have been badly misled if they think otherwise[5].

The political rhetoric of disability often includes the statement that there are six million disabled people in the UK. This figure was indeed produced by the Office of Population Censuses and Surveys[6,7], but interpreting it raises a host of questions which are usually by-passed in

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public debate. However, one fact is certain: at least four million disabled people are of pensionable age.

DEFINING DISABILITY

It is very important to understand that disability is an old word which has gradually acquired different meanings. For example, nineteenth-century Poor Law legislation specified five categories of need: children, insane, defective, sick, and the single category 'elderly/infirm'; 'disabled' was not one of the five. Later in the nineteenth century the blind and the deaf emerged as further categories, but the term 'disabled' seems mainly to have been restricted to the consequences of injury, especially in war or at work. For a long time it was therefore linked with what is now rather imprecisely called physical disability.

The American political sociologist Deborah Stone argues:

all societies have at least two distributive systems, one based on work and the other on need...A successful resolution...must provide a rationale for assigning people to either the work-based or the need-based system...It must also provide a validating device...a means of applying the rationale to individual cases[8].

Looked at this way, all public welfare services and benefit payments are clearly political issues. While the 'validating device' for children and old people can be as simple as an agreed age, defining other categories needs complicated judgement. Traditionally, our profession has been required to set relevant defining standards and make individual judgements. Whether other people do these things better has always been a matter for debate.

A trend to rationalize the diverse categories of need was presumably inevitable. In the USA and the UK, and indeed internationally, disability has emerged as a very broad, politically simplifying category, useful to legislators and claimants alike. It is salutary to remember that the word meant nothing like this in the 1940s when British geriatric medicine was launched, and that the title of an important Act of Parliament in 1970 still included the phrase 'Chronically Sick and Disabled'. Attempts to include mental illness in the category have been quite recent and are still incomplete.

That 1970 Act was a major landmark. It was criticized because its requirements were not mandatory, but it did at least help to set a new climate of opinion and made possible several good practices we now take for granted, such as the provision by local authorities of personal aids and domestic building adaptations. Meanwhile, several physicians worked at improving the terminology of disability so that needs and benefits should be most suitably matched. Recognizing that pathology, functional loss and social and economic disadvantage were not necessarily in proportion with one another, Philip Wood devised the sequence

impairment—disability—handicap

which would logically follow from aetiology and pathology. In 1980, the World Health Organization (WHO) advocated a classification system based on these three concepts[9].

This helped understanding but had disadvantages. It was useful to have a concept—'impairment'—to mean anatomical or functional deficiency or loss, unrelated to cause on the one hand and to social consequences on the other. However, it sandwiched disability as some quality between impairment and social disadvantage, defining it as deficient performance of what professionals call activities of daily living. It helps to recognize that the three concepts had their roots, not in the experiences of disabled people but in the provision of services: impairment is what doctors diagnose, disability is what therapists treat, and handicap is what social workers deal with (Warren M, personal communication).

CHANGING ATTITUDES

Until about 15 years ago the big post-war growth of disability charities, pressure groups and self-help groups was almost all on behalf of disabled people. Parents founded what is now called Scope, and physicians founded what is now Age Concern. But as part of the widespread change in social attitudes and expectations which we have all experienced, disabled people have fought and have been encouraged to find effective ways of putting their own case. If there really are six million of them they have six million votes, and politicians of all parties would rather hear directly what they have to say than those who claim to speak for them, but who all too often have their own agendas, however heavily disguised. From at first being only 'politically correct', listening to disabled people has become socially and administratively respectable, although it has yet to become an accepted part of the way things are.

It is now correct to speak of the disability 'movement'[10,11], inviting direct comparison with radical political movements of other kinds. The movement is international, and not surprisingly some of the major influences have come from the USA. Because the USA constitution incorporates the principle of human rights, and because its Democrat-bequeathed social security payments are matched by very few state services and benefits in kind, for American disabled people it was both appropriate and necessary to take things into their own hands. They had the model of the black population's successful appeal to civil rights and the similar strategies of American feminism, and their numbers were significantly boosted by disabled veterans of the Vietnam War.

Two significant American initiatives have been copied in the UK. The first Centre for Independent Living was established at a university in San Francisco in the 1970s, after which the idea spread rapidly. Each centre is managed and run by disabled people and provides information, peer-group counselling, practical support and a forum for action[12] (pp. 40–2). There are some flourishing British examples (here they are called Centres for Integrated Living) although their number has remained quite small.

Second, in 1990 *The Americans With Disabilities Act* established disabled people's rights in respect of employment, the provision of public services, and access to public buildings and telecommunications. They were:

Short title and definitions
Employment
Public services
Public accommodations operated by private entities
Telecommunications
Miscellaneous

A useful commentary on the Act has been published[13]. Last year Britian got its *Disability Discrimination Act* which covers much the same ground (Table 1), but its requirements are so hedged round with exonerating clauses that one distinguished lawyer has described it as more like a colander than a binding code[4] (p. 1). It scrupulously avoids any mention of rights, and the concept of a national disability tribunal—which would have had authority to arbitrate on conflicts of interest—has been rejected in favour of yet another quango whose advice can be heeded or ignored by the Minister at will. The Act says nothing about hospitals but does not exclude them either: significantly, the National Health Service (NHS) Executive has published policy statements on employment and access to buildings[14].

Table 1 **Contents of the *Disability Discrimination Act 1995***

Disability (definitions)
Employment
Discrimination in other areas:
  Goods, facilities and services
  Premises
  Enforcement, etc.
Education
Public transport:
  Taxis
  Public service vehicles
  Rail vehicles
The National Disability Council
(Supplemental; Miscellaneous, Schedules)

To be fair to the government, it has been caught out before. The mobility allowance and independent living fund (now the disability living and severe disablement allowances) and the attendance allowance each led to far higher social security spending than had been forecast, not to mention the notorious costs of residential and nursing homes. That is why payments to subsidize mobility are still unjustly age-limited. The government believes it cannot afford yet another open-ended commitment, and rival estimates of the cost of two ill-fated disability rights bills only serve to show what uncertainty there is. What the Act does do, is to open up more scope for the cumbersome process of challenging deficiencies and bad practice in the courts with some limited success against deficient provision of social services. So the *Disability Discrimination Act* will be tested by experience.

THE POLITICAL STRATEGY

During the past 30 years, politically active disabled people in Britain have adopted two strategies and both have produced useful results. One has been to work with the establishment, making friends and alliances within the professions and charities and in Parliament, seeking insider influence to change attitudes, reform administrative practices and secure gradual change. The drawback to this is the perpetual risk of tokenism: one or two disabled people recruited to a large group, sometimes quite cynically to make the group appear respectable but by sheer force of numbers virtually powerless, incapable of representing the full interests of disabled people in all their complexity and without the backing of a representative body of disabled people to do so. But a good example of the way in which partnership can work is a joint initiative of the King's Fund, the Prince of Wales' Advisory Group on Disability and University College Medical School in respect of under-graduate medical education[15].

The second approach began with overt confrontation, an early example of which was a policy statement on behalf of a group calling itself the Union of Physically Impaired Against Segregation. It included the following passage:

Since the means for integration now undoubtedly exists, our confinement to segregated facilities is increasingly oppressive and dehumanising[12] (p. 36).

This indignation behind the rhetoric is only too clear. (The passage comes from a challenge to the policy of building residential institutions for disabled people, like the NHS 'units for the young chronic sick' which were being created—on the advice of geriatricians among others.) Disabled people are regularly lumped together in categories, and they had begun to retaliate: the medical profession, in particular, was seen as a powerful unified

force, in control of their destinies and a particular object of antagonism.

One group of activists began to develop a new philosophy which was very influential. It was a direct challenge to the clinical thinking exemplified by the WHO. The concept is simple. At first it was seen in terms of barriers, extending the physical fact of barriers like steps, unmanageable doors and inoperable lifts into a metaphor for all the disregard and misunderstanding which disabled people encounter most days of their lives. For example, presbyopic people have impairments, with the right spectacles they are not disabled but without them they are. By analogy, wheelchair users in a well-designed building are not disabled but in a badly designed building they are. People with impaired communication skills are less disabled if employers are willing and able to employ them to their fullest ability.

The argument was developed further. Although impairment is what the WHO nomenclature says it is, disability is the outcome of the interaction between each person with an impairment and her/his environment: physical, economic, social or cultural. The philosophy became known as the social model of disability, and Michael Oliver has drawn up a table showing ways in which he thinks it differs from the conventional 'medical' or 'individual' model (Table 2). His emphasis is on collective social responsibility, and on transferring power to disabled people who become stronger if they make common cause with each other.

At least initially, the social model generated sharply polarized views, with antagonism and disbelief which was not just among able-bodied people. Even now, only a
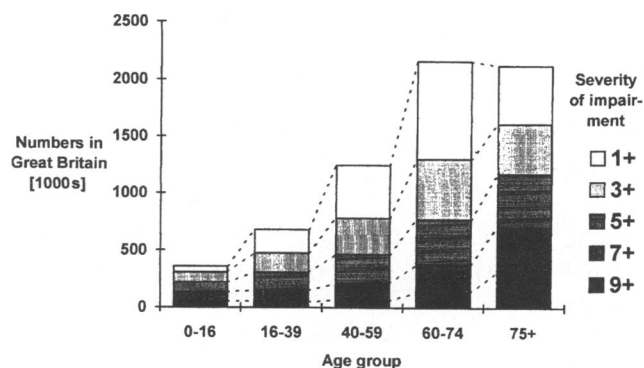

Figure 1 **Six million disabled people (From *OPCS* 1988/1989). See References 6 and 7**

minority of disabled people have heard of it and understand it, and some are unconvinced that it matches their experiences. But what is impressive is the wide variety who have accepted it with enthusiasm, precisely because it does express their experiences very well. Significantly, they describe it as liberating. If being disabled is not something of which to be ashamed, against which one must battle personally to the best of one's ability and be grateful for all the help one can get, but instead a recognized social status which should bring with it certain civil rights, the perspective is dramatically shifted.

Some of the currently fashionable terminology is challenged too, not just for the sake of it but to make sure that this social model is properly understood. For example, given its much broader view of disability there is no virtue in separating it from handicap which is in any case regarded as a demeaning, pejorative term. By definition, people do not 'possess' disabilities, so 'people with impairments' is a legitimate description but 'people with disabilities' is not. 'The disabled' has been unacceptable for many years. 'Disabled people' accurately describes what they are and leaves the matter at that.

Another example is the political and professional use of the word 'care', seen as yet another implication that people needing assistance must be subservient. 'Community care' is not an adequate description of what disabled people have a right to, and 'carers' are much better called 'assistants'. To some extent this formalizes the tension between carers and their dependants with which the health service is all too familiar: but it is making an important and positive point as well.

Every philosophical theory, of course, raises questions, and the social model of disability is no exception. For example, it leaves open the tricky political question of who are and who are not disabled, about which some of its keenest exponents tend to be evasive. The much-quoted figure of six million in Britain was estimated on the basis of the narrow, activities-of-daily-living view of disability, not disability according to the social model (Figure 1).

Table 2 **Models of disability (From *A Charter for Disabled People Using Hospitals, 1992*)**

The medical or individual model	The social model
Personal tragedy theory	Social oppression theory
Personal problem	Social problem
Expertise	Experience
Medicalization	Self-help
Adjustment	Affirmation
Care	Rights
Professional dominance	Individual and collective responsibility
Control	Choice
Individual adaptation	Social change
Individual identity	Collective identity
Individual treatment	Social action
Policy	Politics
Prejudice	Discrimination

Table 3 **Some comments on rights (summarized from Beauchamp and Childress, 1994[17], pages 76–77)**

Only part of a more general account of morality	Valid moral and social purposes
Still need a theory about the appropriate exercise of rights	Express international moral standards
Social ideals and principles of obligation are equally critical to social morality	Sources of personal protection, dignity and self-respect
Often unneccesarily adversarial	

Politically active disabled people have so far been substantially in the 16–60 age group, although they recognize no age limits to the models they propose. Some of them argue in favour of self-definition, which could produce some surprising results.

An instance comes to mind of an elderly man who regarded tetraplegia due to Guillain–Barré disease (from which he was slowly recovering) as an illness, but his lifelong stammer as a disability. Examples like that would undermine any idea that the social model only fits severe impairment, but what of unstable conditions and the severest impairments of all, such as multi-infarct dementia, end-stage Parkinson's disease or Alzheimer's disease? For these, surely, care and the 'medical model' probably are the dominant considerations. And although self-definition of disability might be acceptable in a debate about moral rights, it would certainly not be acceptable as a basis for allocating benefits.

Another issue is the status of rights, still a matter for debate in jurisprudence and moral philosophy (Table 3). On the one hand, it is argued that rights must be conferred by law and, if not, they are simply claims[16]. On the other hand, there are theoretical arguments to show that they exist independently of any statute, a belief which is now popularly accepted[17]. Whatever the view, they do provide some protection, not only against tyranny but against the individual injustices that are inevitable in any social welfare system. Human rights can be universalized and internationalized, and for individuals they confer dignity and self-respect. But rights may also compete with one another, can only exist alongside generally accepted principles of obligation, and can also be unnecessarily confrontational. It follows that they can only be part of a more general account of morality[18].

Yet what is impressive is the way in which the disability movement has grown and developed, both in the UK and internationally. There has been a steady stream of new ideas and research, with stimulating, creative debate and a serious attempt to generate a fair representation of disabled people's outlook. Several academic posts have been created. Twenty years ago none of this existed.

In 1989 the Committee on Disability of the Royal College of Physicians was asked to discover ways in which the College might work in partnership with leading organizations of disabled people. Representatives of these organizations suggested working on the barriers that disabled people face in ordinary general hospitals. The upshot, in February 1992, was *A Charter for Disabled People Using Hospitals* which the College published jointly with the Prince of Wales' Advisory Group on Disability. The *Charter* deals with four main topics: attitudes and approaches to disability, getting the hospital environment right, health risks, and management and training. Among its four appendices are a summary statement on the social model of disability and an example of the questions that might be asked in an audit.

The *Charter*'s authors then learned that several groups had begun to audit disability access in their local hospitals. But we could not discover much about positive outcomes. Through its Research Unit the College is now itself funding an audit project involving a partnership of seven hospital teams. As a prerequisite, each team has an active group of disabled people's representatives. The project includes census surveys of disabled patients and pilot experiments in disability awareness training. We also welcome relevant information from any source: a project bulletin, *Access and Awareness* (published by the College free of charge), should be one means of sharing it. If at all successful, the results should give at least some idea of how far the *Disability Discrimination Act* should apply to hospitals, with insight into some of the more general questions I have been raising. A second edition of the *Charter* is due in 1997.

CONCLUSION

It is time to summarize the evidence in terms of the implications for geriatricians. I have argued that the politics of disability has moved significantly away from social welfare to an agenda determined by disabled people on their own behalf. The development has been in three stages: disabled people getting their act together, evolution of a

Table 4 **The politics of the disability movement: some implications for geriatricians**

Consulting disabled people	To help us professionally
	To help educate our colleagues
Assimilating the social model	As an aid to rehabilitation
	To reappraise conventional strategies
Recognizing rights and entitlements	When we act as our patients' advocates
	Working to remove barriers in hospitals

theoretical model, and the appeal to ethical and legal rights (Table 4).

From the first stage we can learn how to consult and involve disabled people, not just as friendly patients but as sophisticated providers of a body of opinion: (a) to help us in the art of remaining professionally committed while delegating most of the decision-making and action (good opportunities occur during the later stages of rehabilitation); and (b) to help us educate our colleagues in matters of general concern about disability of which we know they are not well enough aware.

We can use the social model of disability: (a) to encourage in our disabled patients something of the 'liberated' feeling which I have mentioned, to see themselves not as society's unfortunate, marginalized victims but as owners of a status which confers recognized civil rights; and (b) to rethink some of our conventional approaches which may be wrongly cast in the medical mould: units for the young chronic sick were one example, and some day hospitals may well be another.

Finally, we may be able to use the legislation: (a) when we act as advocates for our patients as they meet service deficiencies and bad practice; and (b) when we give [as we should] our full support to managers and others in improving the hospital environment, as *A Charter for Disabled People Using Hospitals* has outlined.

In summary, the disability movement is now a major contributor to the politics of disability. The full implications of its theories still have to be worked out. But it is already the valid articulation of a collective view and is therefore of the greatest importance regardless of what that view may be. It has supplied a healthy challenge to conventional wisdom and has made a valid appeal to law. Its case is argued regardless of age. Above all, it has generated a vigorous climate of new, constructive debate.

When all health professionals have learned to think of someone with a hemiplegia not as 'an old man with a stroke' but as a disabled person with rights and entitlements, we shall be well on the way that disabled people are asking us to take.

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